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LETTER TO THE EDITOR

Palliative care for patients with hematological malignancies—a case series

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Dear Editor,

Despite significant therapeutic advances in the last decades, more than half of all adult patients with hematological malignancies (ICD 10: C81–C95) will eventually die from their disease (53.6% in Germany; [3]). Specialized palliative care (PC) institutions, that are characterized by a multidisciplinary team approach in order to improve the quality of life of patients with advanced and progressive disease, have gained broad acceptance in the care for patients with solid tumors. However, patients with hematological malignancies are considered to be underrepresented in specialized PC services [4, 5].

Patients with hematological malignancies had significantly later access to PC services, defined as the interval from first PC consultation until death (13 versus 46 days) [2], and a need of explicit PC concepts for patients with hematological malignancies undergoing stem cell transplantation has been claimed [1].

We therefore reviewed all patients with hematological malignancies at our specialized PC institution in order to define underlying clinical and disease specific characteristics, the subjective needs of these patients, the environment of care, and different modes of PC support, and tried to outline a specific PC approach that could serve as a first fundament and framework for closer PC/hematology cooperations.

Within 31 months (October 1, 2006–April 21, 2009), 79 patients with underlying hematological malignancies were treated at the Department of Palliative Medicine in Goettingen/Germany (5.1% of 1,555 PC patients total). Most patients (34 patients; 43.0%) were treated on an outpatient basis/PC home care service, while 33 patients (41.1%) also required inpatient palliative care. Ten patient contacts (12.7%) were limited to PC consultation service, and two patients (and relatives) were solely supported by PC volunteer services, at home and on a hematology ward, respectively (Table 1). In further 15 documented cases, PC services were contacted by the hematology department, but PC support was not initialized as care concepts were modified before transfer (6/15=40.0%) or due to shortage of a free PC unit bed (9/15=60.0%). Six of the waiting patients died while being on the waiting list for a PC unit transfer (6/15=40%), one of them on the same day PC services were contacted .

Aggressive lymphoma and acute leukemia, as well as myeloma, were the most frequent entities.

Pain was prevalent in 29.1% of cases (23 patients), 43.4% of those suffered from myeloma. Instead, the request for PC was predominantly (56.9%) motivated by psychosocial or nursing-related demands or general support needs for the patient and his/her family.

For the referred patients, the PC approach encompassed

- counseling and pharmacotherapy for pain, dyspnea, fatigue, loss of appetite, and other measures of symptom control
- tailored therapeutic interventions like symptom-guided blood product substitution, anti-infective therapy or antineoplastic therapy, as well as wound care or

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Table 1 Demographic and clinical characteristics (n=79)

Demographic characteristics	
Mean age (years)	65.6 (min 23, max 85)
Male	42/79=53.2%
Female	37/79=46.8%
Mode of hematology/PC interaction	
Inpatient PC unit	33 patients
Outpatient liaison service	34 patients
Consultation service	10 patients
PC/hospice volunteer service (PC contacted but no further interaction)	2 patients (15 patients)
Underlying disease entity:	34 patients
Aggressive lymphoma with allo PBSCT	2 patients
Aggressive lymphoma w/o allo PBSCT	25 patients
- subgroup T-cell origin	5 patients
Acute leukemia with allo PBSCT	4 patients
Acute leukemia w/o allo PBSCT	18 patients
Multiple myeloma/plasmocytoma with allo PBSCT	5 patients
Multiple myeloma/plasmocytoma w/o allo PBSCT	12 patients
Indolent lymphoma	8 patients
Chronic leukemia	2 patients
Aplastic anemia	2 patients
Osteomyelofibrosis	1 patient
Leading problem for PC involvement:	
General support needs/nursing/family/final phase	45 patients
- subgroup encompassing wound care	3 patients
Pain	23 patients
- subgroup multiple myeloma	10 patients
Dyspnea	8 patients
Neuropsychiatric symptoms	2 patients
Refractory diarrhea	1 patient

individual modifications of nutrition and infusional therapy. Aspects of blood product substitution, the eventual changes in transfusion requirements, the indications to modify or even restrict previous transfusion concepts with regard to end-of-life care aspects were addressed in 31 patients/39.2% of cases.

– supporting individual disease-coping strategies by psychological interventions. This proved especially helpful in situations where disease trajectories and prognostication were uncertain.
– advance care planning of precautionary and preparative measures for possible emergencies: bleeding, dyspnea, pain, and other end-of-life crises were anticipated by open communication. Instructions and medications (like on-demand medication for dyspnea, restlessness, or pain) were given in order to facilitate home care and to avoid involvement of emergency medical services at the end of life.
– inpatient consultative PC services: numerous patients have been cared for by hematology services for years, and antineoplastic and supportive measures may prove useful throughout the disease; therefore, an "as-needed" consultative approach will permit continuous hematological care.
– strengthening medical home care and outpatient nursing: facilitating home care included day and night contact options, early involvement of social services, and a flexible readmission policy that offers inpatient service if home care failed.
– involvement of relatives, friends, and other non-professionals like community healthcare providers into home care. As general support needs were high (e.g., due to general weakness) but focal symptoms requiring specialized care not always present, non-professional support proved helpful for continuing care at home.

In our case series, the major therapeutic challenges were related to social problems (discharge planning, organizational tasks, home care, and family support) or psychical problems. Psychological consultations often aimed to provide relief for the patients' (or the families') ambivalence towards realistically understanding the narrow prognostic limitations but still hoping for disease stabilization or even clinical improvement. Reassessment of transfusion requirements with regard to altered treatment goals proved to be a major medical and ethical controversy in almost half of our patients.

We found a cohort of patients that did not necessarily suffer from focal symptoms, as described in epidemiological surveys of general PC patient populations, where, for instance, pain is reported to be a major clinical problem in 81.7% and dyspnea in 20.2% [6].

Eleven patients (13.9%) came from an allogenic stem cell transplantation background. For this particular group of patients, the transition from curative intervention to a PC approach is considered to be especially difficult, regarding the maximum efforts for cure from an otherwise fatal disease, accepting a high treatment-related morbidity and mortality. Transplanters who are about to decide to seek PC support might ask whether they had given up too soon, or if they should have better given up their curative efforts a long time ago. Several observational studies with stem cell transplantation patients showed that the introduction of a hospice team earlier in the disease process did not shorten survival or dismiss hope, but appeared to improve symptoms and allowed better planning [1].

Our case series illustrates the need for a specific PC concept for patients with hematological malignancies. From a PC perspective, traditional thinking in PC that suggests a "common pathway" for all disease entities at the end of life [7] have to be abandoned beforehand. The hematological perspective ought to consider that PC is more than pain therapy: it provides numerous multiprofessional competencies in the medical, nursing, social, psychological, spiritual,

and ethical field that can (and should) be utilized within continuous hematological care.

Both approaches to patient care, PC and hematology, can be expected to benefit mutually from intensified communication that meets the specific needs of our patients.

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